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ABSTRACT

The terminal progress report of the Socio-Behavioral Study Center for Mental Retardation summarizes research activities and results of the Center's three major programs. The Community Research Program studied the epidemiological aspects of mental retardation in the community, including identification and classification of retardates, investigation of prevalence, and delineation of the natural history of retardation in the community, including interactions with the family, neighborhood, and community agencies. The Hospital Research Program studied such problems as use of medications, morbidity and mortality rates, prevalence of seizures, frequency of ward movements, and social and organic factors affecting rehabilitation and prognosis. The Computer Support Program developed necessary computer programs for data analyses in connection with the two other program areas. An extensive list of publications by the Center's staff concludes the report. (KW)

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Pacific State Hospital

Pomona, California

March 31, 1972

TERMINAL PROGRESS REPORT

Socio-Behavioral Study Center for Mental Retardation
(MH-08667-01-07)

EC 041 665E

In compliance with the Public Health Service publication, Grants for Research Projects: Policy Statement (Revised July 1, 1967), the following Terminal Progress Report is submitted

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TERMINAL PROGRESS REPORT

General Statement of Aims:

The Socio-Behavioral Study Center for Mental Retardation (MH-08667), presently under the direction of Richard K. Eyman, Ph.D., was established to continue the work of previous data processing, community, and computer projects.

The socio-behavioral research team was divided into three operating areas. The Community Research Program studied the epidemiological aspects of mental retardation in the community. Among the specific aims of this research were the identification and classification of suspected and diagnosed retardates, the investigation of the prevalence of retardation, the comparison of groups of retardates identified through various case-finding methods, and the delineation of the natural history of retardation in the community, including interactions with the family, the neighborhood, and the community agencies.

The Hospital Research Program studied such problems as the use of medications, morbidity and mortality rates, prevalence of seizures, and frequency of ward movements. An emphasis was placed on the development of statistical models for studying the epidemiology of mortality and morbidity in an institution and on the evaluation of social and organic factors affecting the rehabilitation and prognosis of patients.

The Computer Support Program developed necessary computer programs for data analyses in connection with the two other program areas. A more detailed account of the research activities and findings of the Center follows.

Comprehensive Progress Report:

1. Definition. It is well known that the mentally retarded are an ill defined and poorly circumscribed group of individuals (6,14,34,46, 54,55,10 ,122,154,155,164,166,175,242,254,276), but in several studies undertaken at the Center (6,31,46,53,54,103,122,128,148,222,254,276), it has been possible to support statistically the clincial notion that there are two major types of retardation. One type of retardation, in which organic pathology is usually demonstrable, is most commonly identified by a pediatrician or a neurologist. A second type of retardation is reflected in an incapacity on the part of the individual to meet the demands of the social environment, and this type is most commonly identified by a psychologist, psychiatrist, or educator. Mercer (103,222,254, 276) has pointed out that the greatest confusion concerning incidence and labeling of the mentally retarded exists in the second type, whose general behavior may strongly resemble that found in the first.

The clincial and social system perspectives differ in the emphasis on organic etiology versus the functional nature of the impairment, including the psychological and socio-cultural components of causation. As indicated by Tarjan (53,128), however, clarification of these conceptual differences between somatic and psychologic medicine will not resolve all the problems

of definition because retardation transcends medicine. Probably no medical conceptualization will prove completely satisfactory and it will remain necessary for representatives of other professions to define retardation from the viewpoint of their particular disciplines.

In clincial practice today, the diagnosis of retardation depends on the concurrent presence of significant impairments of intelligence and adaptive behavior (53,80,140,216,225,230).

Mercer (276) has investigated the IQs of a representative sample of 480 children, seven months through 15 years of age, in the city of Riverside. Each child was assigned a weight to correspond to the number of persons of the same ethnic group, socio-economic level, and age in the community. Using these weighted frequencies, it was possible to prepare an estimated IQ distribution for the entire community in this age range and for three significant subgroups: English-speaking Caucasian children (Anglos), who comprise 80% of the total population; children of Mexican-American heritage, who comprise 12% of the total; and Negro children, who comprise 8% of the total.

Figures 1 and 2 show how IQ norms depend upon the composition of the normative sample. Current practice either excludes members of minority groups from normative samples or else includes them according to their proportion in the population. Having established norms in this fashion, clinicians frequently proceed to operate as if the norms are universally applicable and the presence of subgroups irrelevant. In either case, minority group children frequently appear as "abnormals."

In this same study, 240 social agencies in Riverside were asked to report all the mentally retarded persons known to them; duplicate nominations were identified and a clincial case register containing all persons under 50 years of age was developed. Table 1 compares the percentage of each ethnic group appearing in the register of "retardates" nominated by these agencies with the percentage of each group in the general population of the community. The essential point is that a statistical definition of "normal" used on a heterogeneous population containing significantly different subgroups, tends to define certain subgroups as "abnormal."

From these findings, Mercer concluded that there should be three definitions of "normal": a medical definition based on organic pathology; a statistical definition based on the normal curve; and a social system definition based on the analysis of the normative structure of each social system. Definitions of "abnormality" generated by these three approaches are likely to converge when the cases being examined are extreme and when they involve visible biological abnormalities. However, when there are no biological signs and the evidence is primarily behavioral, the outcomes of the three approaches are likely to diverge.

In interstitial cases, the pathological approach encounters difficulty because its criterion of "normal" rests on a biological functional analysis and there are few, if any, biological signs and symptoms. The statistical approach is likely to label culturally different subgroups as "abnormal." A social system approach anchored in the norms of individual subgroups, is likely to reflect the social reality more accurately.

Figure 1

Estimated IQ Distribution with Mexicans-Americans and Negroes Included According to their Proportions in the General Population

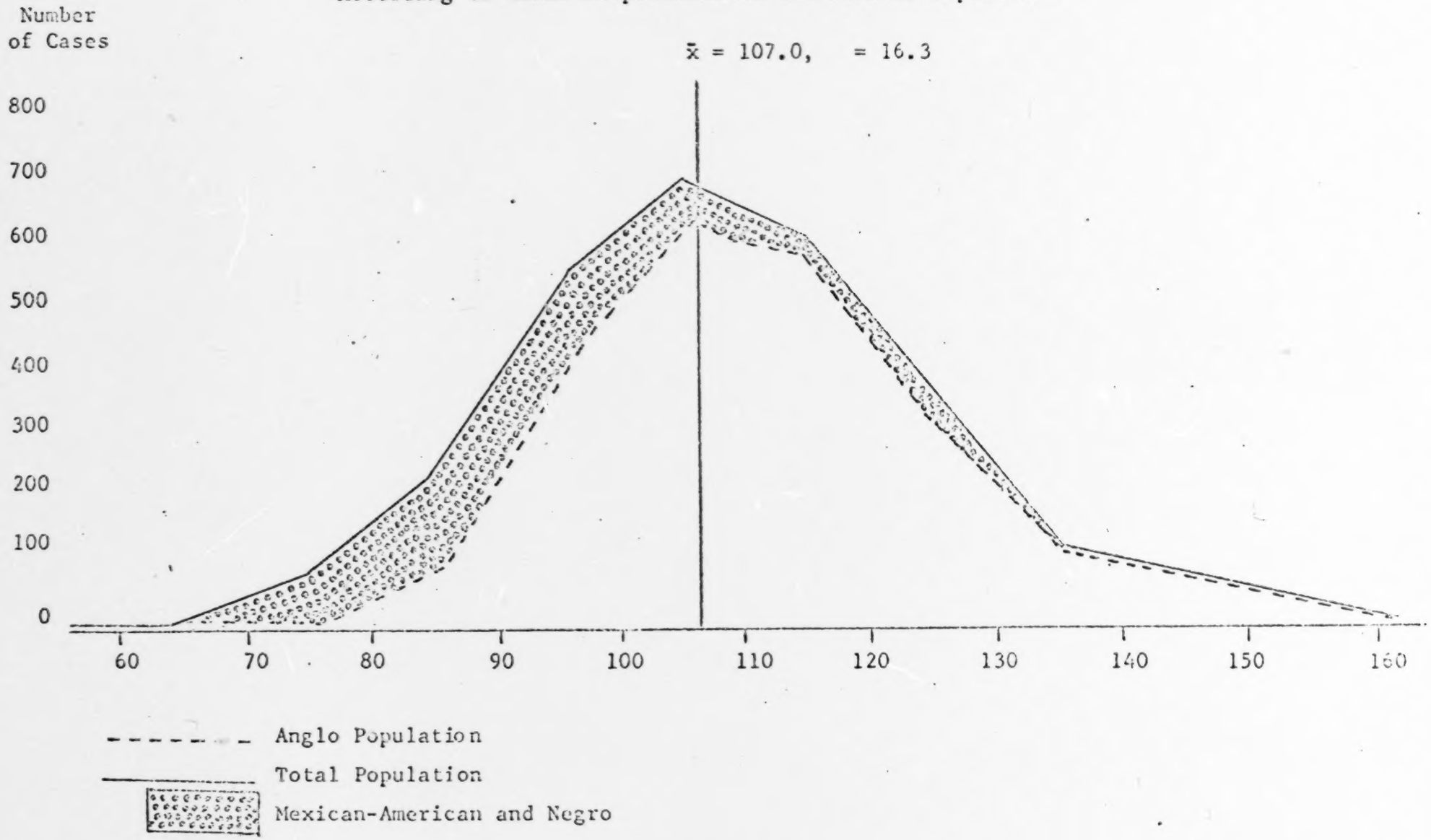


Figure 2

Estimated IQ Distribution with Mexicans-Americans and Negroes

Given Equal Weight to the Anglo Population

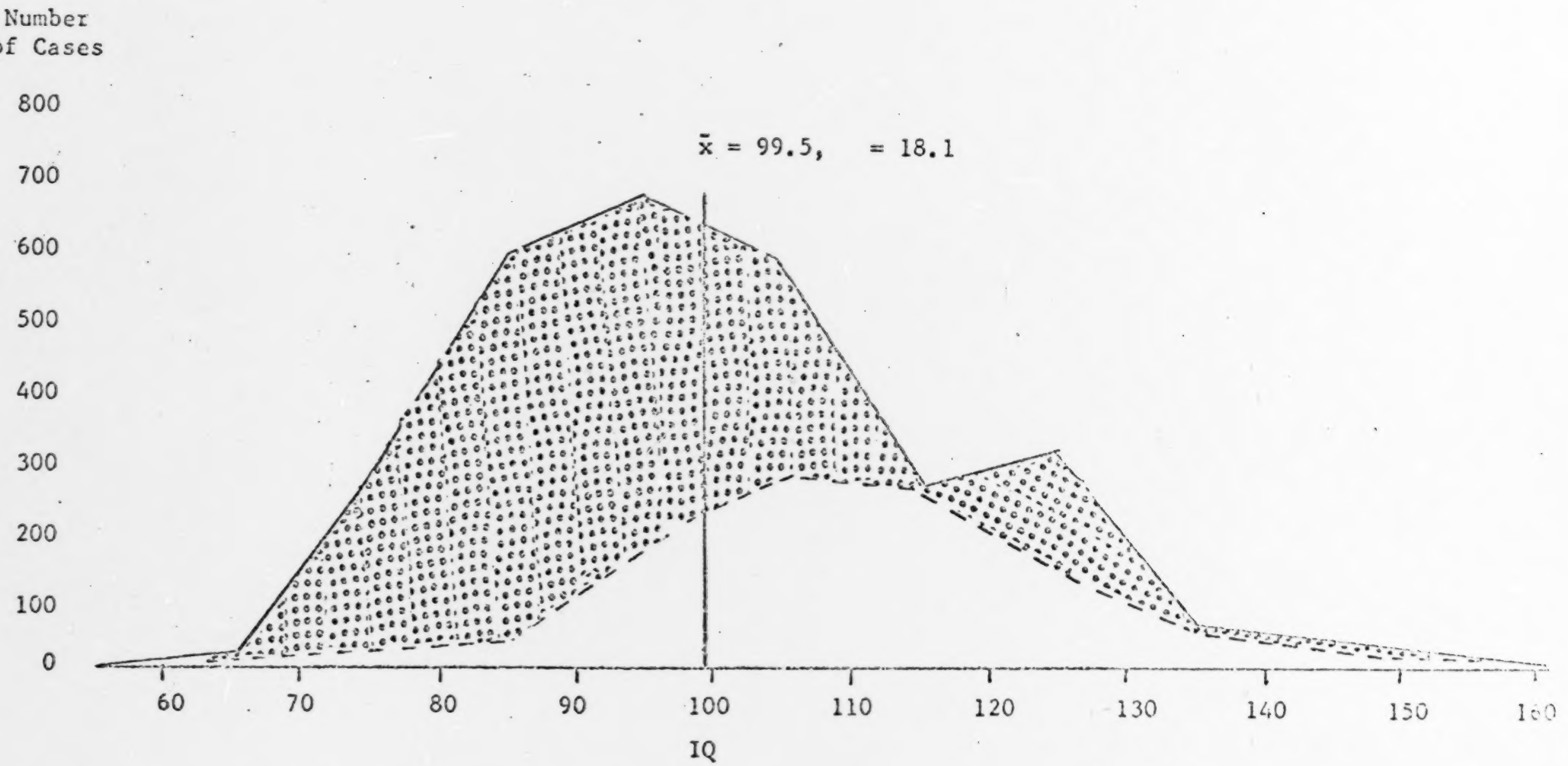


Table 1

Composition of General Population and Clinical Case Register by Ethnic Groups

Groups	Anglo	Mexican	Negro
Total Community (N=6,901)	82%	10%	7%
Mental Retardates (N=664)	53%	32%	12%

Note.--Percentages do not add to 100% because other ethnic groups have been omitted.

Thus, each approach has strengths as well as limitations. When organic damage and disease processes are clearly involved, the pathological approach is the most powerful conceptual tool. When there are behavioral components in the phenomenon being studied which cannot be directly related to physiological processes, then a statistical approach may be useful if the entire population being studied has been exposed to essentially similar socialization processes, and has internalized similar cultural norms. However, when the population being studied is not homogeneous and has not been exposed to similar socialization processes nor internalized similar cultural norms, then social system approach is to be preferred. Although this involves a more complex model, which may prove cumbersome in empirical studies, it promises to be a more illuminating map with which to explore culturally determined variations in behavior. Only further research going beyond the limits of mental retardation will substantiate the merits of this approach.

Intelligence can be measured with reasonable accuracy, but it has been demonstrated that even with IQs below normal, individuals are able to function adequately in a family setting or social group (49,54,60,63,82, 97,114,117,135,141,143,145,161,222,254,276). The measurement of adaptive behavior is in its infancy (16,77,80,110,135,161,169,230,275,276). Its pase is slowed by the need to study the nature and quality of the social climate in which the individual is functioning. A fair evaluation of the status of the large group of retardates whose IQs range from 50 to 70 would undoubtedly reveal that a substantial proportion of these individuals would be helped by the development of adequate social environments in which they might mature (141,211,222,254,275,276).

2. Epidemiology. Problems of definition lead to problems in epidemiology. In planning services, accurate data on the incidence and prevalence of retardation are essential. Unfortunately, only limited information on institutionalized retardates is presently available (1,4,8,9,18,22,35,70, 73,78,79,88,93,94,105,112,122,124,129,130,137,144,148,149,155,169,183,210, 214,216,225,241,242).

It is generally accepted that 3% of the newborn will manifest symptoms of mental retardation (129,134,155,170,182,211,275). Owing to higher mortality rates among retardates and the number of children diagnosed as retarded who are absorbed into the general population upon reaching adulthood, the 3% prevalence rate applies only to the mildly retarded of school age. A 1% prevalence rate might be more appropriate in categorizing the "visible" mental retardates in the general population. This is merely a statistical abstraction, however. The rate of retardation will depend largely upon the social climate and the adequacy of community resources, such as the number of teachers per class and the number of school counselors per pupil.

If an individual--infant, child, or adult--is identified as retarded, what is the probability of certain types of outcomes, e.g., retention in the home or community, death at home, or admission to an institution? The only outcome for which some information is presently available relates to the probability of institutionalization. Pacific State Hospital serves a population of about five million people, and the Center has

attempted to study the process of admission to an institution (9,18,54, 69,70,124,129,134,161,210).

Table 2, based on some unpublished calculations by Wright, shows the relative probabilities of institutionalization of retarded individuals by age and IQ. Data on admissions to Pacific State Hospital between 1962-1964 and the results of the household survey conducted in Riverside in 1963 were used to arrive at the estimates given in the table. Using a prevalence rate of 1%, one can estimate the probabilities of admission by age and IQ. While the data do not lend themselves to calculations of absolute probabilities, they do permit estimation of relative probabilities.

The relative probability of admission is lowest for the individual with IQ > 50 and age 6-19 years. The value is given as 1, and all other probabilities are given in relation to this value. The probabilities divide into two groups; those that are high and those that approximate the low value of the reference group. The relative chances of placement for the moderately-severely retarded child are 30-70 times greater than for the individual in the reference group. The value of 36 for the young, mildly retarded child is due to the inclusion of the young child with Down's syndrome and with IQ > 50. Also included here is the young, mildly retarded child with signs of organic impairment. The low values for the moderately-severely retarded adult indicate that there is a low probability of their placement, and they will likely remain within the home or some community facility. Thus the data indicate that it is the moderately-severely retarded child who has the highest probability of institutionalization; the mildly retarded, although numerically the most frequent, have the lowest probability of admission.

a. Speed of hospitalization. Most hospitals have lengthy waiting lists, and parents who have finally made the decision to place their child are often faced with a 12-24 month or even longer period of waiting for a vacancy to occur (124). Thus, the selection process employed by the hospital staff represents one factor in the speed with which a patient is admitted.

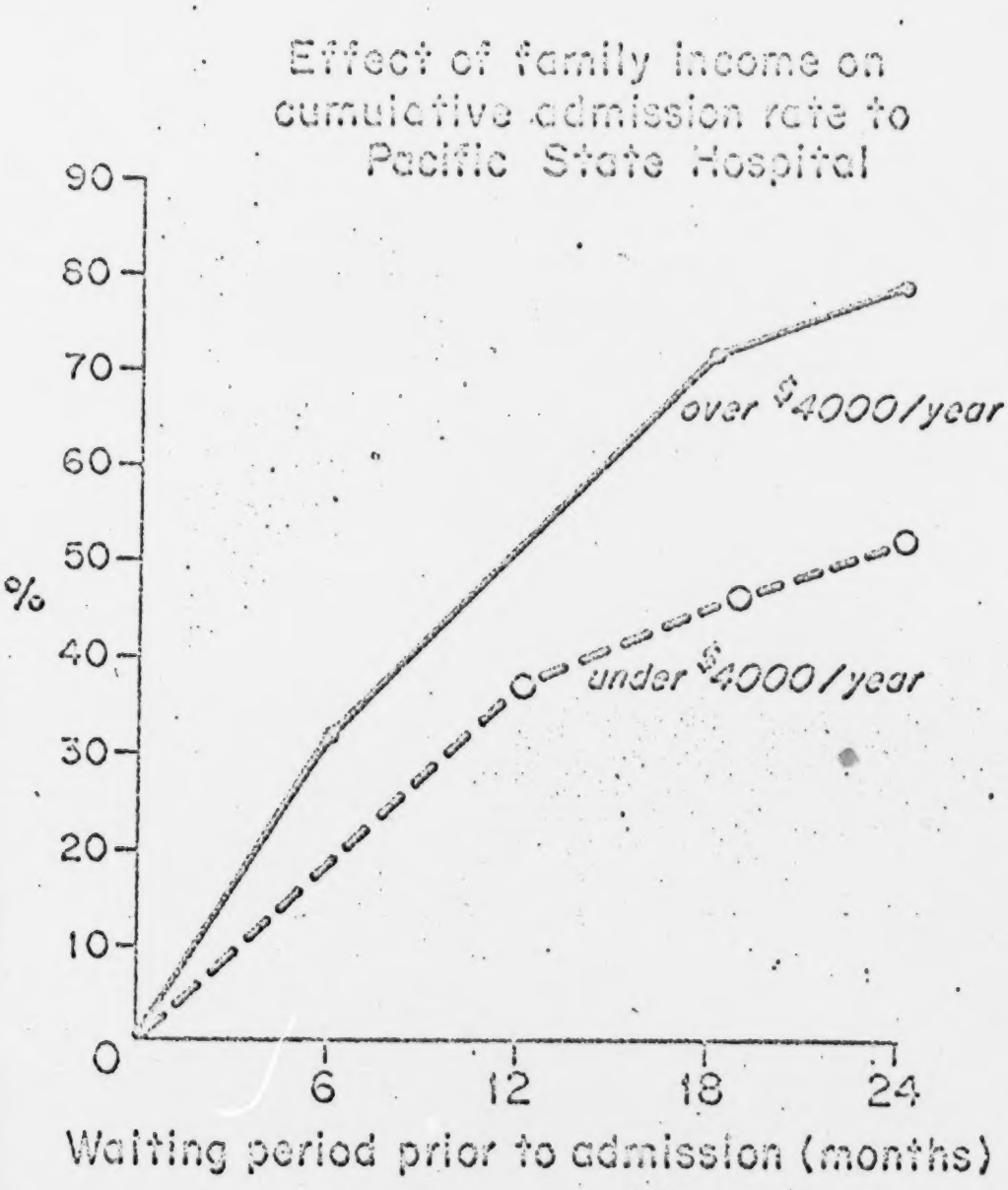
The relationship between characteristics of the patient and his family and the speed with which the hospital staff selects the patient for admission have been studied at the Center (113,124). Speed is defined in terms of the length of time between the patient's being placed on the waiting list and his admission to the hospital. Numerous variables were studied; the only significant association was between family income and speed of admission. This relationship is shown in Figure 3. The waiting period in months is shown on the abscissa, the cumulative percentage of admissions on the ordinate. Families with annual incomes over $4,000 had a cumulative admission rate of almost 80% by the end of two years; families with annual incomes under $4,000, an admission rate of about 55%. No association could be established with such characteristics as the age, IQ, or severity of physical handicaps of the patient, or with other characteristics of the family.

Table 2

RELATIVE PROBABILITIES FOR INSTITUTIONALIZATION OF A MENTALLY RETARDED INDIVIDUAL BY AGE AND I.Q.

	AGE IN YEARS			
I.Q.	6	6 - 19	20 - 24	24
<20	73	45	7	6
20-49	30	20	3	1
>50	36	1	3	2

Figure 3


Effect of family income on cumulative admission rate to Pacific State Hospital
90
80
70
60
50
40
30
20
10
0
%
over $4000/year
under $4000/year
6
12
18
24
Waiting period prior to admission (months)

An explanation for these results is not readily apparent. Possibly they relate to the greater skill of higher income families in verbalizing their problems and in accepting and recognizing the problem of mental retardation in their child (124); possibly the lower income families have greater access to other public service agencies, and are less adept in expressing their problems to the hospital staff. Further study of this problem is in progress.

b. Composition of the institution. The institution is often regarded as a custodial unit; patients are placed as a last resort; the hospital represents the "end of the road." This static concept of the institution is no longer valid; hospital programs and community resources are serving to change this concept to one that recognizes the hospital as a dynamic structure (54,64,70,73,95,128,129,130,134,182,183,214,241,242).

What are the characteristics of an admission group of patients? Which characteristics are associated with release, retention, or death within the institution? Considerable information on these questions has been obtained in a series of studies which were begun at the Center in 1955 and are still continuing (1,4,5,7,8,9,10,11,12,14,18,21,22,35,36,37,46,48, 54,70,88,99,122,130,134,155,183,210,214).

One of the earliest facts to emerge from these studies was that newly admitted patients are divisible into at least two groups, as discussed previously. Some other findings of these studies concern the changes that are occurring in the characteristics and movement of patients over the last decade. For the sake of brevity one of the most recent studies (210) will be summarized for this purpose. Two admission groups or cohorts were compared; the first of these was admitted in 1948-1952, the second in 1958-1962. Comparison of these two cohorts indicates that significant changes are occurring in 1) the characteristics of admitted patients, 2) mortality rates within the hospital, and 3) release rates for selected groups of patients. The results are important in assessing the changes that are occurring in public and professional attitudes toward the placement of the retarded, in instiutional programs, and in medical practice generally. Some of these findings will be presented in the following tables and figures.

1) Admission characteristics. Figures 4, 5, and 6 each show a characteristic of the newly admitted patient with the percentage of patients in each cohort who demonstrated this characteristic.

A significant decrease has occurred in the number of "functional" diagnoses (Figure 4); the term "functional" can also be interpreted as "cultural-familial" retardation. In this diagnostic category, retardation is mild, minority groups are overrepresented, and behavior disorders are a frequent presenting complaint (6,9,31,46,54,122,134,211,214,275,276). This change is not associated with the assignment of these patients to different diagnostic categories, but rather with the development of special education classes in the community. In the decade covered by this study, the number of persons in special education has increased by a factor of 6, but more important is that the number of Negroes and Mexican-Americans referred to special education classes has increased by a factor of 10. Thus,

Figure 4

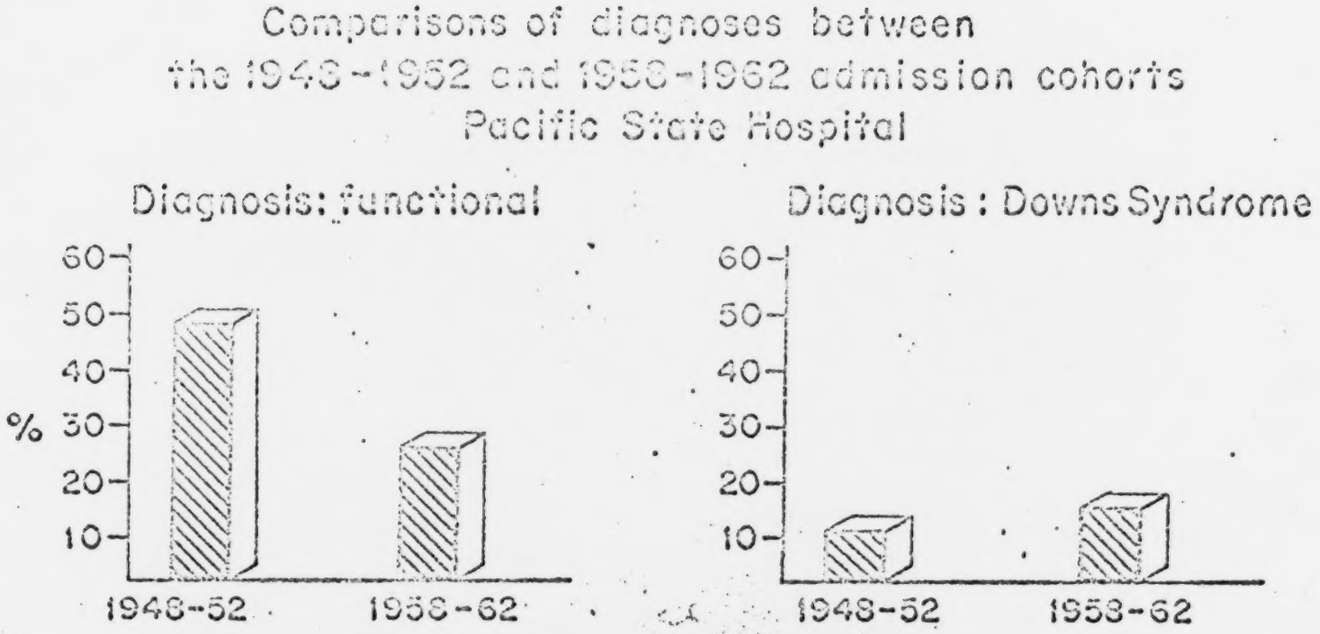


Figure 5

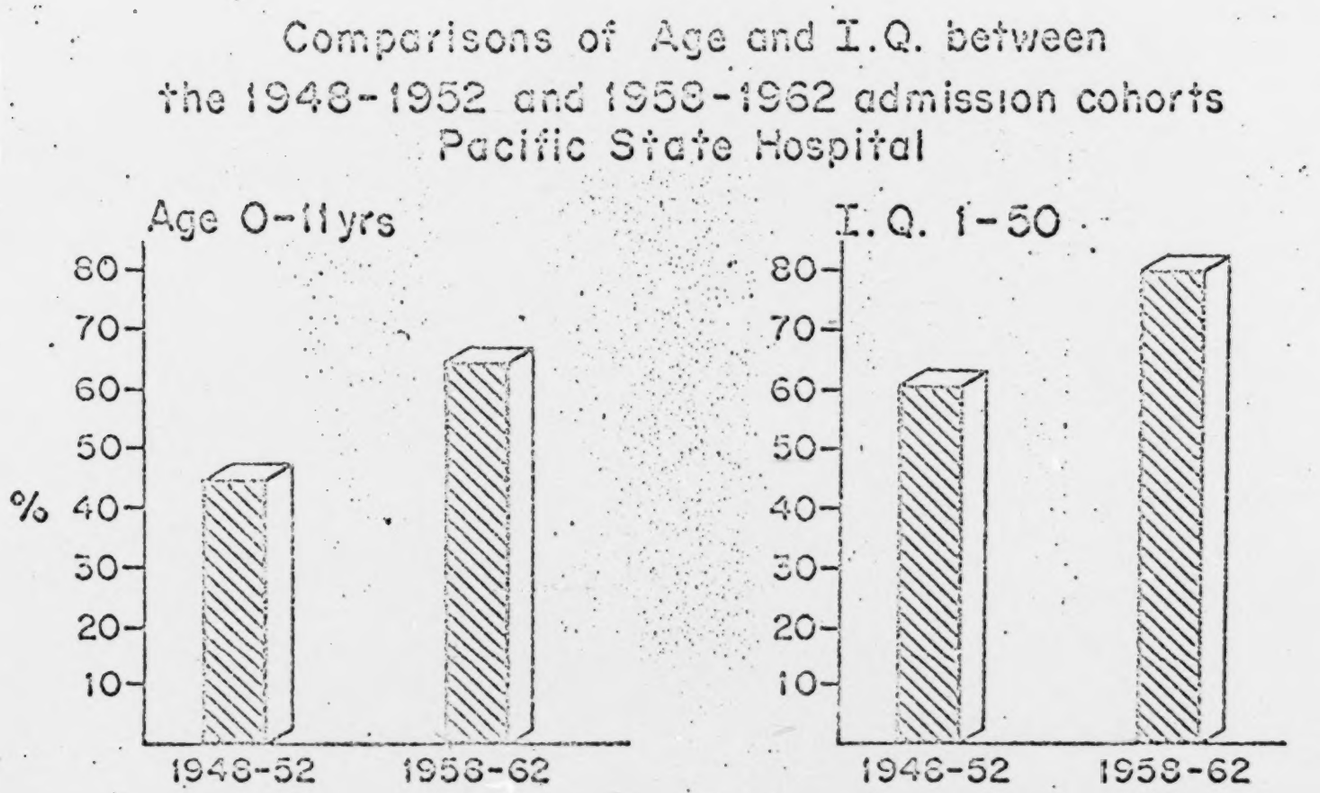
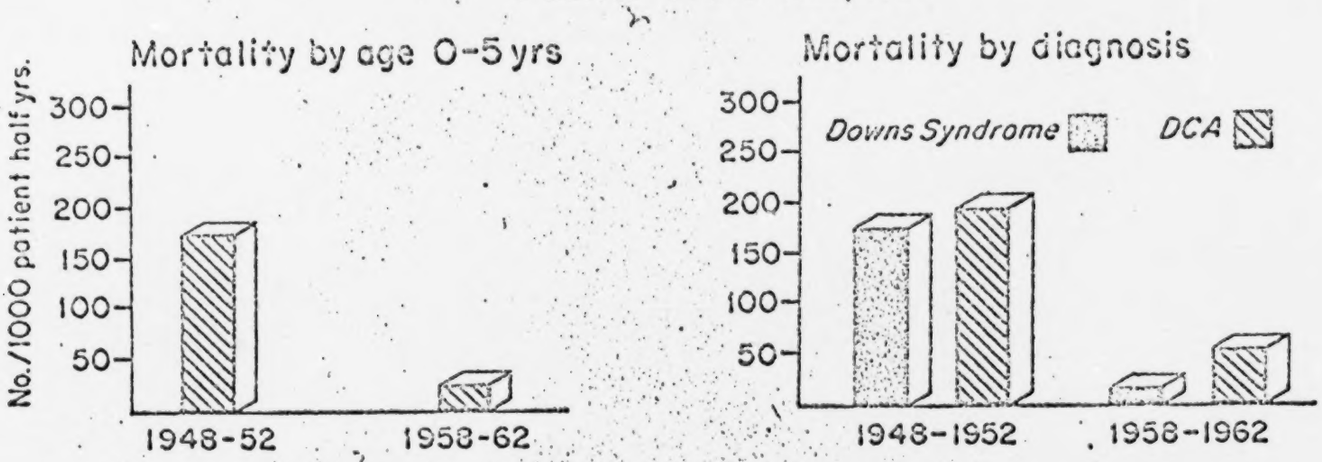


Figure 6

Comparison of mortality by age and diagnosis between the 1948-1952 and 1958-1962 admission cohorts Pacific State Hospital



the shift has occurred from placement in an institution to placement in special education classes within the community (103,115,128,129,145,161, 182,209,254,275,276). The figure also indicates that the proportion of children with Down's syndrome has increased by a factor of 2. This is a reflection of a tendency to admit more moderately and severely retarded children and those with specific somatic diagnoses.

Further data on this point are shown in Figure 5, which shows changes in age and IQ in the two cohorts. In the left-hand diagram, it can be seen that there is an increasing tendency to admit younger patients--from 45% in the earlier cohort to 66% in the later cohort. Further, the degree of retardation is more severe; the right-hand diagram shows that almost 80% of the patients now being admitted are in the severe to moderate range of retardation.

2) Mortality rates. One of the most serious problems in the young, newly admitted patient with severe retardation is the high mortality rate. Significant changes associated with improved medical and nursing care have occurred in the mortality rates in the decade which separates the two cohorts (Figure 6). The mortality rate per 1000 patient half-years is shown along the abscissa. In the earlier cohort, mortality in patients admitted between 0 and 5 years of age was about 175/1000 patient half-years. In the later cohort, the mortality rate fell to 23/1000 patient half-years. This change is associated with additional medical and nursing care; the use of mass prophylactic treatments, such as immune globulin for infectious hepatitis; mass suppressive techniques, such as chemotherapy for amebiasis and shigellosis; the more liberal use of antibiotics; and systems for identifying on admission those patients with a high probability of dying (183).

Mortality by diagnosis is also shown in Figure 6; the sharp reduction in deaths of patients with Down's syndrome and with developmental cranial anomalies can be noted.

The data presented indicate that there has been an increase in the number of young, severely and moderately retarded children and a sharp decrease in mortality. Inevitably this should lead to an increased number of patients in the hospital, with associated problems of overcrowding, personnel shortages, inadequate budgets, etc. That this has not happened is because of the development of hospital release programs which return the patient to the community (21,37,54,75,95,99,130,135,137,139,155,161,214).

3) Release rates. During the decade which separates the two cohorts, significant changes were occurring in release rates for patients. Release can be expressed in terms of family care, home leave, and work leave. Figure 7 shows release rates for patients according to age in the earlier (left) and later (right) cohorts. The abscissa shows the 4-year follow-up period in half-year intervals; the ordinate shows the number of days that the average patient spent outside of the hospital. Each curve represents one age group.

In the earlier cohort, the patients who were released most frequently were in the older age groups; they spent about twice as much time on leave

Figure 7

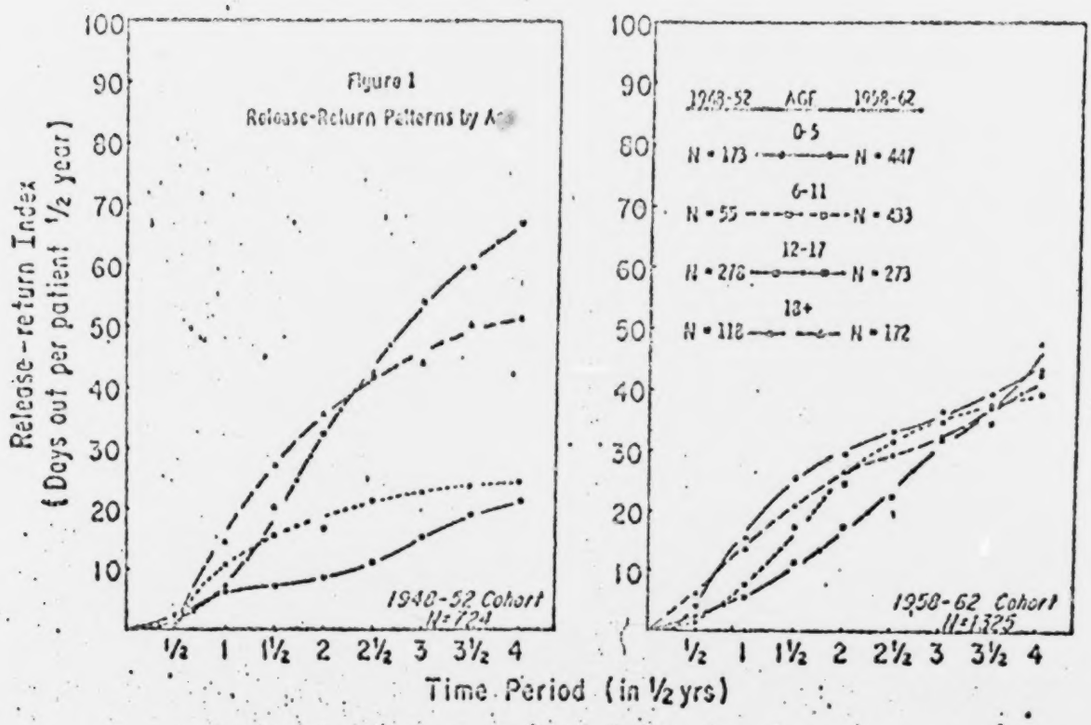
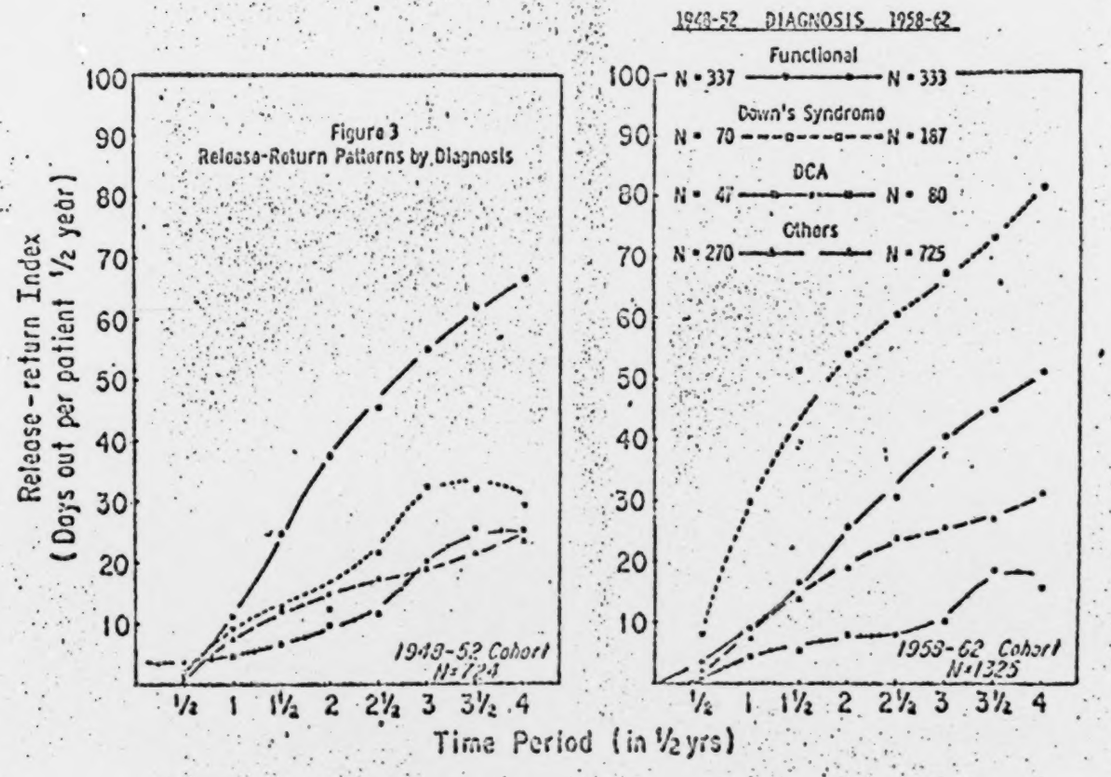


Figure 8



status as did those in the younger groups. In the later cohort, the data show that the younger groups now spent about twice as many days on leave status as those admitted a decade earlier.

Figure 8 compares the release-return indices of the two cohorts by diagnosti categories. In the earlier cohort, the group with functional retardation had leave experiences that were between two and three times as good as those of the other diagnostic groups. Patients with Down's syndrome and other somatic diagnoses spent relatively little time outside the hospita In the later cohort, the greatest number of days on leave was spent by patients with Down's syndrome; in the earlier cohort they spent an average of 20 days on leave/half-year and in the later cohort, 60 days/half-year.

Thus, the changes in the two cohorts are striking; there is a trend toward admission of the younger group of moderately and severely retarded children, and it is likely that this trend will continue. At the same time, there is a trend toward returning many of these to the community. Community programs can be used in lieu of or as a follow-up to institutionalization, and can provide for increasing numbers of patients. The state institutions will be used primarily for older and more severely handicapped individuals (254).

c. Foster care. The marked increase in the release-return indices for the young moderately retarded patients requires further comment. In 1952 a family care or foster home program was initiated by the hospital. Over 800 patients are now in foster home care (155). In this program, the State pays $150/month/patient to the caretaker, as compared with an average of $400/month to maintain the patient in the hospital. The program is suitable for a wide variety of patients, ranging from young children to adults, and from the severely to the mildly retarded (5, 36,37,54). Patients who are excluded include the adult infirm and adolescents with severe acting-out behavior. The patients are usually returned to the hospital for acute illness requiring medical care; otherwise they remain in the caretaker's home for varying lengths of time. For some patients, the foster home represents an interim program away from the hospital; for others, it is a step toward eventual discharge from the hospital; for still others, it is the ultimate goal since they will remain indefinitely in the home of the caretaker.

The psychological benefits to the patients are obvious (155,182). The success of the program can also be measured in financial savings; these data are shown in Table 3. The gross savings are about $2.4 million/ year. The net savings are somewhat smaller because the state continues to provide medical and social services to the patients in foster care. However, additional savings accrue because if these patients were maintained in the institution, they would require an additional 10 wards, and each ward costs an average of $1.2 million.

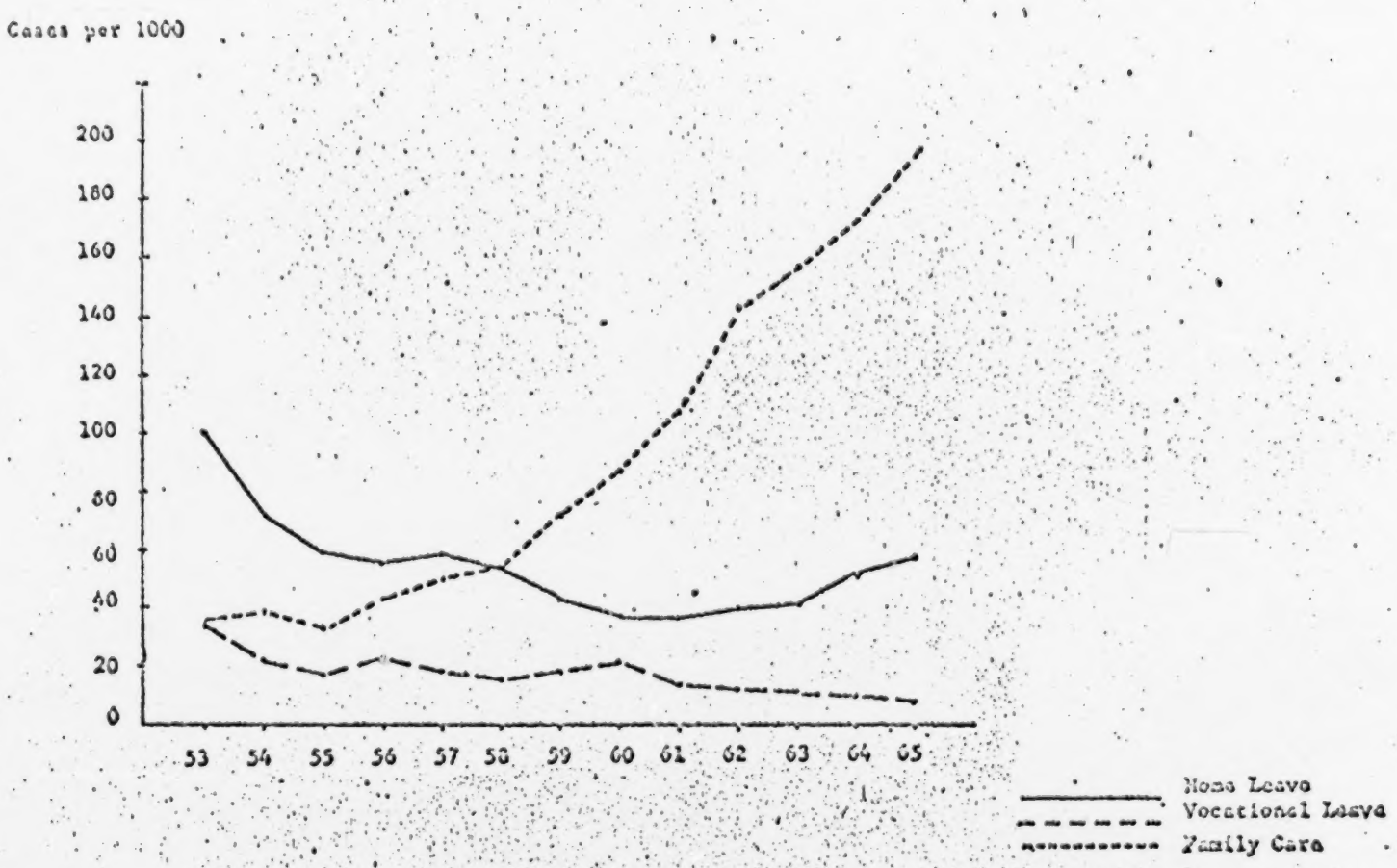
Two other types of release programs are available; home leave and work leave. Figure 9 shows the numbers of patients on these programs as well as on family care (155). It is obvious from the data shown that fewer patients are being placed on work leave. (The figures have been

Table 3

COMPARISON OF COSTS OF FOSTER HOME CARE VS. IN HOSPITAL CARE (PACIFIC STATE HOSPITAL)

Item	In Hospital	Foster Home
No. patients	2400	800
Cost/patient/year	$4800	$1800
Savings	$2.4 million/year	
Construction cost per ward	$ 1.2 million	
Estimated cost of new wards	$12.0 million	

Figure 9


Cases per 1000
200
180
160
140
120
100
80
60
40
20
0
53
54
55
56
57
58
59
60
61
62
63
64
65
Home Leave
Vocational Leave
Family Care

adjusted to account for changes in patient characteristics.) The reasons are related to increasing automation and a decreasing need for unskilled and semi-skilled labor. It is far easier to find a place in the community for the dependent child than for the semi-independent adult (37,54,117, 135,161,163,275). This problem emphasizes the need for sheltered workshops for further job and vocational training (119).

d. Developments in residential care. Two groups of patients are usually retained within the hospital; these are the profoundly retarded individual with severe physical handicaps, and the mildly retarded teenager with acting-out behavior (1,4,5,10,21,37,54,55,79,95,130,210).

Imagine a 16-year-old Negro male who has come to the attention of the probation department because of vagrancy, truancy, or minor theft. He is found to have an IQ of 60, and since he comes from a broken home, he is admitted to the institution. He has been living in the community, has established friendships, belongs to a "gang," attends school, and participates in the social and athletic activities of the average teenager. Suddenly he is placed in an institution where his life is carefully regulated; he is told by the hospital personnel what he may and may not do; he is separated from his friends and his established way of life.

How does such a person adjust to the hospital? The process has been documented by Edgerton, among others (27,42,48,58,59,75,76,135), and the essential events are as follows: 1) by comparison with the more severely retarded, the "low grades"; 2) by identification with peer groups or "gangs" within the hospital; 3) by the acquisition of a girl friend; 4) by attaining some degree of economic success through car washing, gardening, yard work, or assignment to the laundry, dining room, or ward work; 5) by achieving a dominant position in the ward; 6) by establishing good relations with the hospital employees; 7) by the use of normal defense reactions, e.g., denial of hospital authority, and by peer support.

Thus, given a period of time, the initial process of "mortification" leads to one of "aggrandizement" which may assure the patient of an eventual release from the hospital. As Edgerton and MacAndrew have also shown, however, other retardates are not so fortunate (79,80,114).

Throughout history, state hospitals have been thought of as depositories of human beings who are considered misfits in the community. Because of the public image of the state hospital as a "warehouse," it has often been difficult to secure funds for research and the development of creative programs, particularly those designed for integration with the community (93). Research was, therefore, limited to a description of the type of patients admitted, length of stay, and, in some cases, outcome (94,128, 129).

The research conducted by the Center represents one exception to this generalization. In addition to the studies summarized above, other investigations can be mentioned which have had an impact on residential care at Pacific State Hospital. The utility of typologies, previously discussed, for administrative and medical purposes can be illustrated by two examples. Sabagh (8) computed mortality rates using age, sex, race,

and other variables and clearly demonstrated that there are distinct differences in such rates, depending on the characteristics of the patients. Because of the limited number of deaths, however, it was possible to compute mortality rates for only a few cross-classifications, and the effects of interaction among the variables were difficult to assess. Accordingly, Miller (46) utilized the latent class model to classify patients into two groups. One of these groups contained almost all the patients who would be likely to die within the first year after admission; thus, membership in this group was predictive of a greater chance of death. Predictions of those newly admitted patients who were most in danger of dying were then sent to the hospital staff for a seven-month period. Only 4 patients admitted during this period died--all from the high-risk group. Since it was expected that 13 patients would die, it could be considered that the experiment was a success. The medical staff had been alerted to those patients who might die and were able to take preventive action. In fact, certain staff members verbally reported that they regarded the prediction of mortality as a challenge to their medical skills. The physicians felt that the study was at least a partial success because it had alerted them to the types of patients who required special attention and enabled them to provide such attention. The overall well-being of the patients had been improved. After the predictions were no longer made, however, the mortality rates returned to their former levels. Life tables are now being constructed for determining the life expectancy of retardates admitted to Pacific State Hospital by sex, age, IQ, diagnosis, ambulation, and toilet training.

A second example of a useful typology is provided by the work of Dingman (73). The transmission of enteric diseases is known to be oral-fecal in nature. On the basis of patient characteristics, it should be relatively easy to identify those patients who are likely to contract such diseases as shigellosis and amebiasis, as well as those patients who will be effective carriers of these diseases. Relevant variables are degree of toileting training, feeding habits, ambulation, arm-hand use, age, and diagnosis. These variables were dichotomized in such a way as to maximally predict contraction of shigellosis and/or amebiasis within the first year after admission, and rates were computed for all combinations of these variables. By determining the combination of variables that characterized each patient, a prediction of the likelihood of contracting the diseases could be made. The initial reaction of the medical staff was not to utilize the typology, but rather to mass treat <u>all</u> patients in an attempt to totally eradicate the diseases. Over the long run, however, the expense and possible dangers of such drug use apparently led to more selective treatment, based on information supplied by the typology.

Numerous other studies which had an impact on patient care can be summarized. Mosier, Grossman, and Dingman developed a growth laboratory in which anthropometric measurements have been collected since 1960. The data are used by the medical staff for diagnosis and treatment of individual patients (17,28,33,47,62,68,105,111,121). It has been established that the patients are physically smaller than normals, mature later, and exhibit differences in stature by diagnostic type.

Studies assessing the incidence of various communicable diseases in the hospital and surrounding community (78), frequent medical problems of the retarded (34,55,74,170), and the type of acute medical facilities necessary to treat them (95) have received attention from other institutions for the mentally retarded, in California and elsewhere. Recently, mortality and cause of death at Pacific State Hospital were analyzed over a 20-year period in relation to significant historical events (admission rates, medical facilities, etc.). The results called attention to the importance of the early postadmission period during which mortality rates due to pulmonary diseases are particularly high.

As already reported, there have been several research projects devoted to patient movement in and out of the hospital. The major aims of this research were to relate patient movement to patient characteristics, to provide information which could be used for predicting which patients were most likely to enter and leave, and to determine the effects of such movement on the future composition of the hospital population. Examples of the application of this information have appeared in the literature (38,39,49,53,56,88,98,99,137,155,192,214).

Despite the advances cited in the use of available resources, the prognosis of many institutionalized retardates remains bleak because of manpower needs (19,133,144). This fact was further documented in a study by Eyman, based on a four-year follow-up of the 1962-1964 admission cohort (217). Data were presented which demonstrate that ambulation and toilet training are ctitical variables for community placement. Under "standard" care, those who are admitted in a non-trained condition show a poor prognosis. Those who improve tend to make their progress during the first year of institutionalization. Intensive programs can alter the outlook in a favorable direction.

Tarjan (129) commented earlier that in the large residential institution, patients are exposed to social forces which are often similar to those encountered in the outside community. The social environment of the traditional institution, however, with its complete separation of age groups and sexes, is entirely artificial and often fails to assist in personality development (79,93,97,129,135,140,158,174,185). It is vital, therefore, to maintain within the residential setting a community center with recreational and social programs, in which patients may participate in group activities and have as much personal freedom as their level of maturity permits. There must be an opportunity to establish stable relationships with adult figures, usually the employees, whom the patient respects and trusts.

3. Intellectual and Electro-Physiological Assessment. In order to maximize educational and vocational opportunities for retardates of various ages, mentality levels, health statuses, and superimposed physical and psychological handicaps, more research is needed on the appraisal of their specific abilities and disabilities. Toward this end, the Center has devoted a large effort to the intellectual and electrophysiological assessment of retardates as compared with normals.

Studies of the structure of intellect and other models of intelligence in young children and retardates are becoming more frequent (2,3,7,13, 15,16,24,28,30,32,43,45,60,63,72,77,80,82,85,86,100,104,110,116,118, 123,127,131,147,149,150,151,152,153,156,157,171,172,175,177,178,179,181,197,199, 202,206,207,212,215,216,230,239,257). The increase in such studies has been due in large part to the efforts of the Center, which has been responsible for probably half of all the pertinent publications. Some studies at other laboratories have been conducted as extensions or confirmations of this work.

In general, all reports, whether here or elsewhere, have emphasized that intellect is structured, no matter how young the children studied. This finding has held even when the analysis has been limited to scales presuming to measure "general" intelligence, such as the Binet or Wechsler's scales (32,144,149,150,151,153,178,179,180,230). While these may show a large general factor, they always show one or more group factors as well. When they are entered into a matrix with more reference tests, there is less tendency for the general factor to emerge. All studies at the Center were factor-seeking and included a variety of tests, hypothesizing results in terms of separate factors; most of these hypotheses have been confirmed (104).

A partial catalog of the factors hypothesized and repeatedly obtained is as follows:

(a) Verbal comprehension or linguistic ability--the ability to understand language. (SI: Cognition of and convergent thinking in semantic content.) This ability is evident before two years of age.

(b) Ideational fluency--the ability to produce multiple or elaborated verbal responses upon a cue. (SI: Divergent semantics.) Evident as low as four years in normals but not in retardates of comparable MA.

(c) Psychomotor ability, especially that involving eye-hand coordination. (No SI location, as it is not conceptualized within the intellective realm.) Evident in infancy.

(d) Perceptual speed, figural decoding, and figural identification--the ability to match or identify figural materials quickly and accurately. (SI: Evaluation of figural content.) Evident in infancy.

(e) Figural reasoning--the ability to recognize and use forms, especially when coping with change in size, rotation, or completeness. (SI: Convergent thinking in figural content.). Factors (d) and (e) have never separated well and appear to be correlated.

(f) Immediate memory for figural content--the recall of observed stimuli such as figures and toys. (SI: Memory for figural content.) Some evidence for existence in infancy.

(g) Immediate auditory memory--the ability to recall digits, letters, words, and sentences presented for reproduction. (SI: Memory for symbolic content; memory for semantic content.).

Concerning the distinction between the visual and auditory factors in (f) and (g) above, it is worth emphasizing that the work of the Center has consistently, at all ages studied, with both retarded and normal children, obtained separate factors for visual and auditory input whenever it has been possible to compare these on similar tasks. This is so primarily for memory tasks. The separation also was found by Meyers in his factorial study of the Illinois Test of Psycholinguistic Abilities (ITPA) for the decoding process and to some extent for the encoding processes as well (195).

There is also rather convincing evidence that the two auditory memory tasks, forward and backward recital, tap separate ability factors. The function represented by backward recital is not yet identified within the system, but does have some meaningful relation to mathematical success which the simpler forward recital does not (246).

A small start has been made in utilizing structure-of-intellect principles in the pursuit of a theory of mental growth. For example, the above-mentioned study by Meyers on the ITPA showed by factorial means that the nine subscales of that instrument do to some extent separately measure the functions called for by psycholinguistic theory. A theory of differential mental growth associated with subcultural differences had been tested by Lesser (Lesser et al., 1965); a study by Sitkei and Meyers (206) at the Center provided a small replication with four-year-old children. A theory of different mental growth for phenotypically different children, e.g., undifferentiated retarded, brain-injured, etc., has not been systematically tested but has been explicated (30). Structure-of-intellect comparisons of retarded and normal children of comparable MA have shown general similarity, due for the most part, it is believed, to the administration of tests suitable for both groups. Eventually it will undoubtedly be shown that the retarded children cannot achieve to the same extent on factors of the "higher" sort, such as convergent and divergent operations, productions of implications and transformations, etc.

A variety of practical consequences of the structure-of-intellect investigations remain to be implemented. One application would be the reduction of redundancy in testing; factorially similar tests can be eliminated from batteries. Another application would be programming in terms of the description provided by differentiated test results. Strong points of profiles can be exploited in instruction, e.g., the utilization of visual or auditory input where one or the other is clearly superior. Low points can be remediated. Patterns predictive of future problems can lead to prophylactic intervention. Meeker and Meyers (246) have shown the differential relevance of immediate memory processes to school subjects and to behavior constellations in ninth grade boys. Meyers (172) showed that behavior ratings as well as test scores could predict school achievement from kindergarten to fifth grade.

The relationship of impaired intelligence to other behavioral and physical pathology has also been studied (17,28,77,80,105,136,156,170,175,207, 216,239). The results demonstrate increased pathology on both behavioral and physical measures as a function of severeity of retardation.

Electro-physiological studies on the retarded have been ongoing at the Center since 1964. Studies based on normative cross-spectral analysis of the EEG in both retardates and normals are now underway. Based on the evidence to date, normals show greater moment-to-moment variability in shared brain activity due to greater nervous system "plasticity." Results based on visually evoked responses demonstrate a greater latency in retardates than normals. The effect of stimulating the visual cortex using light flashes shows more localization in retardates than in normals. These findings suggest that this area of research may have a significant impact on the diagnosis and treatment of specified types of retardation.

4. Beachhead in Society. In the light of the primary institutional goal of return to the community, residential programs maintain a social service staff to assist the individual in establishing a beachhead in society. Dingman (134,161) and Edgerton (135) showed that many of the mentally retarded can remain in the community only under "protected" circumstances which involve community agencies and programs. A study of a community of 100,000 people revealed that there are some 240 agencies which provide service for a mentally retarded individual (83,134,142, 145,222,276).

In order to study both the prevalence of retardation and the life styles of the retarded in a setting other than the institution, the Riverside study was undertaken (83,211,275). The study proceeded in two ways. The first was to draw a stratified random sample of approximately 10% of the households in the community. Survey interviewers were sent to the households to collect information on all the inhabitants, and a selected subsample was also administered intelligence tests by trained psychometrists. The refusal rate was held to 8% by making every effort to obtain all the interviews possible. It was also established that except for age (the refusals tended to be older), the ascertainable characteristics of the refusals did not differ significantly from those of the persons interviewed (142). The second part of the study involved studying the files of community agencies serving the retarded, and developing a central case register which included all cases which had been brought to the agencies' attention.

It had become apparent even before the study was initiated that the major problem facing epidemiological efforts to identify the retarded lay in defining who fell into that category. Therefore the focus of much of the study was on the labeling processes utilized to identify the retarded. As a further aid in this endeavor, two scales were specially constructed. The first, an adaptive behavior (AB) scale, was designed to measure success in conforming to expected social roles, while the second, a physical disability scale, was designed to measure physical impairment. The retarded were to be looked at in terms of these two scales, as well as IQ, in an attempt tosort out the criteria used by the labeling persons or agencies in making their judgments.

The results of the two approaches, sampling and case register, were very much the same. When social class and ethnic status were related to being identified as "retarded," lower class persons and ethnic minorities

were substantially overrepresented. This was particularly true at the school ages. While at other ages the retardation may not be noticed or may not be considered a problem, the schools are the most likely place that children will be tested and identified as mentally backward. There is a question, however, as to just what is being measured in the testing situation. When cultural factors were related to IQ and AB score, it was noted that approximately 30% of the variance in IQ, but only about 8% of the variance in AB score, was accounted for by cultural factors. This was in spite of the fact that the items on the AB score were intentionally selected to measure conformity to culturally prescribed social roles. It appears that many persons lead a satisfactory life in spite of a low IQ and therefore avoid being labeled as "retarded." This leads to the conclusion that the diagnosis of retardation should involve failure on both IQ and adaptive behavior. Such a dual failure would characterize a person who would be unlikely to be able to care for his own needs in a satisfactory manner.

Nowhere is this problem of culturally related labeling more prominent than among Mexican-Americans. With socio-economic factors controlled, the rate of Negro retardates identified by social agencies in nearly the same as for Anglos, but the rate for Mexican-Americans are still significantly higher. It would appear that language is a critical factor. English is spoken all the time in 91% of the homes in Riverside, but over half the retarded come from homes where it is not. In spite of attempts to make intelligence tests culture free or culture fair, it appears that what is being measured is not innate ability but the degree of "Anglicization," or knowledge of the terms, practices, and values of the dominant Anglo culture. While testing for Anglicization may be a legitimate endeavor in its own right, the practice of labeling a person as "retarded" on this basis is questionable at best. This is a further argument for utilizing a joint criterion of IQ and adpative behavior for labeling retardation. The use of an AB score tends to counteract the bias of the IQ.

These findings shed further light on the question of which percentage cut-off point should be utilized to identify the retarded. There are three criteria in general use. These are the so-called traditional criterion (3% level), the educational criterion (9% level), and the AAMD criterion (16% level). It was noted that raising the levels had little effect on the rate of retardation among middle and upper class Anglos, but greatly inflated the rates of lower class Anglos, Negroes, and Mexican-Americans. The cultural bias of the intelligence test is compounded at higher levels. Furthermore, rates using the traditional criterion more closely approximate those of other major epidemiological studies of retardation and the actual rates of labeling revealed in the clinical case register. It was therefore concluded that the traditional criterion serves best to identify those in need of assistance (275).

Who are the retardates known to community agencies? Do community agencies serve all persons in the field of eligibles proportionately? The answer, of course, is that they do not. Consistent with the findings just discussed, they tend to serve disproportionately more middle and upper status Anglos, more persons with physical disabilities, more persons with IQs

below 70, and more persons of school age than appear in the field of eligibles. Groups which are relatively less known to agencies concerned with mental retardation are low status persons, persons with a Mexican-American heritage, persons with no physical disabilities, persons with IQs over 70, and persons who are either under 5 years of age or over 30. Thus, both the labeling process and the provision of services are highly selective.

The chief concern of the Center's community studies has been and continues to be epidemiological, but several follow-up studies utilizing the household and agency surveys of 1963-1964 are in progress.

These follow-up studies are conceptualized as a series of self-contained and interrelated research projects. In the planning and preparation for data collection and in the execution of field work the studies were divided into two main categories: (a) interview studies of persons nominated by the agencies in 1964 and of persons whose families were originally interviewed in the household survey of 1963; (b) studies which involve re-study of the files of clinical agencies nominating individuals to the clinical register during the agency survey of 1964.

Data collection for the follow-up studies began in May and June of 1968. The studies of the clinical agency files continue at the present time. The interview studies were completed in March, 1969.

The follow-up studies involved the interviewing of five distinct groups of individuals. In each instance, when an interview was granted the same interview was used whether the respondent was a parent, parent surrogate, or relative of the subject. A modified version of the interview schedule was used when the subject or the spouse of the subject was the respondent.

One of the follow-up studies of retardates identified in the 1963-64 community study focused on the problems encountered by parents of retarded children and the personal, public, and private resources utilized in coping with these problems. Further efforts were made to identify services which are unavailable but considered by parents as vitally necessary in their efforts to manage their retarded children.

Of the retardates between 6-19 years of age, the parents of 48% were found and interviewed. Eighty percent of the retardates remained at home, 10% had been institutionalized in a state hospital, 2% were deceased, and 3% were in foster homes. The remaining 5% were classified as in "other" living conditions.

The effects of culturo-linguistic ghettoization on the study of retardation were demonstrated in several of the findings. In the follow-up sample the number of Mexican-Americans was disproportionate to the number expected, based on the original sample of labeled retardates in Riverside. Moreover, in the original study itself, the Mexican-American retarded population was greater than expected on the basis of population considerations alone. As all subjects in the study were nominated by public agencies in the community, the labeling procedures used in making these nominations

have been shown to be crucial (103,145,222,254,275,276). This is especially important when cultural and linguistic dissimilarities are not considered in assessing mental development.

A number of factors were found relating to mental retardation and barrio life within Riverside's Mexican-American community. The most important of these seemed to be language. In the 1968 survey, it was reported that English was spoken "all of the time" or "most of the time" in only 30% of the Mexican-American households in the two barrio areas. This factor undoubtedly relates to the frequency of school-labeled retardation of Mexican-American children.

The Mexican-American group was also exceptional in that income and housing decile were not significantly correlated for them, while for Anglo and Negro groups, the opposite was the case. This is also indicative of a ghettoization factor, since Mexican-Americans tended to remain in the same general area of the community, regardless of income differences, and mobility occurred primarily within the barrio. Religiously, culturally, and familially, the Mexican-Americans appear to constitute a closer-knit ethnic community than the other major ethnic groups in the study. These ethnic characteristics, together with the previously mentioned language factor, have important implications for community efforts to deal with the problems of retardation.

Minority group parents of retarded children revealed in Justice's (249) study of coping patterns that their understanding of the problems of retardation and related programs and services differed significantly from those of parents as a whole. In the first place, minority group parents were less likely to identify mental retardation as their children's most serious problem. Instead, these parents point to physical handicaps among children with low IQs (under 52), and to learning and behavior problems among children with higher IQs (52 and above).

Minority group parents sought public services less frequently than Anglos, indicating either lack of acceptance or understanding of the problem or insufficient information on available programs of assistance. Personal resources were used most frequently for help with all problems by parents of all ethnic groups. The closer the source of support was in relationship to the retardate, the more frequently did such support occur. This seemed to be especially true in the Mexican-American community, because of its emphasis on family continuity and the tight family structure of the barrio. Among public community services, schools and medical services were most used for all problems. Private community services were seldom used for any problems, least of all by the Mexican-Americans.

Differences among ethnic groups were found with respect to an understanding of the need for services and programs for the retarded. Special education programs were most often mentioned by all parents, followed by workshop and work-training, recreation, and counseling. However, 57% of all parents indicated either that no programs were required by their situation, or that they knew of no existing programs. Among this large group, several notable divergencies appeared. Mexican-American parents stated more often that no service was needed or that they were unaware of helpful ones, while Negro parents stated that services were needed, but were usually unaware of the existence of helpful ones. Anglo parents, for the most part, both identified needed services and were more knowledgeable about which ones were available.

Minority group parents of retarded children were generally unaware of the types of services available to assist them with their particular problems. Among Mexican-American groups, it may be hypothesized that this lack of awareness is to some extent due to language deficiencies. Furthermore, the existence of barrios can be seen to be a contributing factor in perpetuating this and other culturally related deficiencies. Public agencies responsible for assessing and labeling retardation may fail to take these factors into account in the process of nominating retardates. To counter this possibility certain innovations may be suggested, such as the employment of more bilingual personnel, the modification of intelligence and achievement tests to meet culturo-linguistic difficulties, and perhaps non-English special education classes.

The striking lack of information among parents, especially of minority groups, points to the need for a more adequate system of dissemination of information. Agencies, both public and private, should cooperate in a referral linkage system designed to expedite referral and introduction to assistance and to avoid duplication of effort wherever possible. Such a system would aid in overcoming many of the communication problems with all parents, but particularly with minority group parents. Justice suggested that a group of "indigenous non-professionals," or neighborhood service center workers, be developed and trained to a semi-skilled level in the initial assessment of retardation and in referring the nominee to appropriate agencies. Such non-professionals, themselves natives of problem areas, would be able to communicate with the parent in his own terms and bring to light the nature and seriousness of the problems of retardation, as well as inform him of the existence of helpful programs and services.

The problems identified by family caretakers, and the resources which they utilize in maintaining retarded children in the community have also been investigated. All family caretakers in a homogeneous service area with patients under age 18 were interviewed. They were caring for 40% of the total number of patients in this age group who are on family care leave from Pacific State Hospital. Demographic information and data collected about perceived problems, coping patterns, and service gaps will enable comparisons between caretaker responses and the responses of natural parents of retardates living in the Riverside Community.

Information was also obtained about the participation of these patients in educational, vocational, recreational, and religious activities. Data abstracted from clinical records provide a history of patient movement and reasons for each move, from the date these individuals were first placed on family care.

This investigation is conceived as the first phase of a project to compare the level of functioning of patients living in the community with the functioning of institutionalized patients. The long range objective will be to evaluate the relative effectiveness of hospital and community programs. In previous studies of family care, the research has focused on patient characteristic caretaker characteristics, and reasons for placement failures (5,21,37). Studies have not been carried out to assess how retarded individuals actually function in different social environments, despite the current emphasis upon community placement as an alternative to institutionalization (129,161). Data from this pilot study will make possible social research directly related to program planning..

The preliminary analysis shows that 51% of the patients in the study homes are profoundly or severely retarded (IQ range 0-35). The caretakers reported wide variation in the availability of different types of services. Two-thirds of the patients were in public schools, most of them attending classes for the trainable mentally retarded. There were no patients in sheltered workshops or vocational training programs, although caretakers with children in the age range eligible for such services were aware of the resources. Further analysis is needed to determine why these programs were not being utilized. Medical services were available and generally considered satisfactory by the caretakers. Both the hospital aftercare clinic and private medical services were frequently used. With the exception of recreation and religious programs, there was minimal use of other public or private resources. Only a very few day care programs were available for the children not attending school, and these had been organized by the caretakers themselves.

The problem that caretakers identified most frequently was public misconception about the mentally retarded and lack of community acceptance. Lack of school programs and other school-related difficulties was the second most frequently identified problem, and behavior problems of the patients came third.

Thirty-seven percent of the caretakers reporting problems said that no one had helped them with these concerns. Forty-four percent had received help from professionals and 35% from relatives and friends, or from the patients' families. (These figures include 16% reporting help from both professional and non-professional sources.) An important resource for the individuals in this study was other caretakers. The most frequent way in which they assisted each other was by babysitting, enabling families to get away from the responsibilities of full-time patient care. They also exchanged experiences and ideas about handling the children.

Caretakers expressed the greatest need for additional recreation and activity programs. Day care, sheltered workshops, and vacation relief services were also named as resources which would be helpful in providing better care.

The preliminary findings of this study suggest the need for critical investigation of public attitudes towards community care for the retarded. Patients have been placed in family care homes for the past 20 years, in rapidly increasing numbers. It is evident from the caretaker's reports that increased community acceptance has not accompanied this trend, although some studies have emphasized this problem (41,57,97,119,143,146,198). Future studies will continue to emphasize the role of community and parental attitudes in the prognosis of children with impaired competence.

5. Research Support. As research projects require new techniques for data analysis, methodological studies have continued to receive emphasis (6,13,23,26,29,31,33,38,39,40,43,52,70,71,74,81,86,98,99,100,120,132,137,138,148,151,159,160,167,168,173,176,180,184,186,188,212,214,215). These studies deal with a wide array of research problems including the evaluation of patient prognosis over time, multivariate methods of classifying the abilities of the retarded, measuring sensory deficiencies, sampling problems, and data manipulation or transformation necessary to handle crude survey responses.

Computer programs available include:

Sample Definition Programs
- PS101 - Case Selection
- PS102 - Collate
- PS103 - Print
- PS104 - Copy
- PS105 - Recode 1
- PS106 - Fortran Sort
- PS107 - File Manipulation
- PS201 - Case Selection from Movement Files
- PS202 - Edit
- PS203 - Recode 2
- PS204 - Boolean Case Selection
- PS205 - Transgenerations
- PS206 - Totaler

Data Description Programs
- PS111 - Frequency Distribution
- PS112 - Correlations
- PS113 - Cross Tabulations with Nesting
- PS114 - Bivariate
- PS115 - Univariate Data Description
- PS116 - Missing Data Correlations
- PS211 - Statistics within Strata
- PS212 - Altab
- PS213 - Sample Plot
- PS214 - Miscellaneous Correlations
- PS215 - Sums, Etc.
- PS303 - Rates
- PS313 - Patterns

Analysis Programs
- PS121 - Analysis of Variance
- PS122 - Student t Test for Correlated Means
- PS123 - Student t Tests
- PS124 - Partitioned Chi Squares
- PS221 - Tests of Homogeneity
- PS222 - Analysis of 2 x 2 Contingency Table: Fisher, Chi Square with Yates Correction, and McNemar Tests
- PS333 - Rowwise Correlated t Tests

Multivariate Analysis Programs
- PS131 - Iterative Factor Analysis
- PS132 - Harris Method for Factor Scores
- PS133 - Stepwise Multiple Regression
- PS231 - Niles Principal Components
- PS232 - Maxplane
- PS234 - Prediction from Regression
- PS235 - Item Analysis
- PS306 - Latent Class Allocation
- PS308 - Factor Analysis II

Estimation and Distribution Programs
- PS141 - Fitting of Frequency Curves of Continuous Variables
- PS142 - Fitting of Frequency Curves of Discrete Variables
- PS241 - Fables
- PS242 - Fourier Analysis
- PS301 - Hotelling T^2

Descriptions of computer programs developed by the staff have been published (61,87,88,98,162,196). A version of the program manual is also to be published by the Honeywell Corporation. Other major programming efforts have resulted in a complete package for reporting the biannual evaluation of patients resident in the hospital and changes in their characteristics over the last half-year period. Morbidity, mortality, and treatment program involvement are similarly reported.

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